



The
British
Psychological
Society



Supporting Families and Staff

Dr Karen Dodd – BPS

Summary

- Group work 1
- Similarities
- Working with families
- Staff issues
- Staff training
- Group work 2

Group work 1

Identifying the key issues

- Families
- Staff

Similarities

- Need to understand the diagnosis and prognosis
- Giving information at the right time and in the right format
- Philosophy of care
- Interventions
- Monitoring changes
- Emotional labour

Supporting families – emotional issues

- Trauma of diagnosis, bringing back emotions surrounding the birth, life expectancy and disability of the person.
- Prior experiences of family and friends being diagnosed with dementia and thus will have ideas about the journey ahead.
- Sensitivity to the needs and beliefs of families, and to see things from their perspective.
- Some carers believe that it is their duty to care and may find it very difficult to accept support and help into their own home, or try to cope even when the person has needs that are greater than they can cope with.

- Emotional labour and pain
- Sensitivity to the small number of carers who cannot cope with seeing their family member deteriorating, and may opt out of being involved.
- Life Story work is one positive way of enabling family carers to maintain a relationship or to stay involved in the person's care.
- Carers often need a great deal of support to prepare for the eventual death of the person they are supporting.
- Advanced Planning can help carers to be involved in sharing future wishes, and to talk through issues and plan for the last months/years of life.

Support issues

- Need for a comprehensive Carer's Assessment.
- Own risk of developing dementia or other age related conditions.
- Carers need to have prompt access to appropriate information about supports and resources available, including short breaks (both within and away from the home), individualised budgets and direct payments, and aids and adaptations included assistive technology.
- Need to be involved in assessments and review meetings, even when their family member does not live with them.

Staffing issues

- Staff are the key component in ensuring that people who live in any form of supported living or residential provision can 'live well' with dementia.
- Staffing numbers need to be appropriate to ensure the person is safe and that staff are able to meet the person's changing needs.
- In practice, this means that staffing levels will need to increase as the dementia progresses. By mid-stage dementia, people usually require waking night staff to ensure safety, and often an increase in staffing levels to manage self care and to respond to the distress that people with dementia often exhibit.

- Excellent dementia care can only be provided by a consistent staff group. Agency staff, unless very well known to the person, should always be avoided as this can add to the person's stress level.
- Staff may not have known the person when more able and not understand the extent of deterioration.
- The best care is provided by staff who are flexible in their approach, deal with changing situations with compassion and humour, cope with the person's declining abilities and can reach out to the person.

Training for staff

- The timing of training is important. It is important that a service is 'dementia-ready' before their residents begin to develop symptoms of dementia.
- Staff need to have a thorough understanding of the person, of dementia and the consequences of having dementia, and then how to adapt their care as the dementia progresses.
- This can only be achieved by having a clear framework to underpin the training and support provided to services.
- Evidence suggests that where staff had received relevant and targeted training that was practice based and person-centred, they displayed an appreciable difference in confidence, quality of care and support and they also reported reduced stress levels.

Training models

- Best outcomes occur when there is interactive training which involves the development of care plans; follow-up consultation and support for implementing care plans; and where there are changes in how the organization understands and responds to people with dementia.
- The importance of developing a shared vision on which to build practice is now well-recognised as the pre-requisite of good care. Without this solid foundation, values, expectations and approaches are likely to differ greatly amongst staff. This will ultimately generate conflict and frustration and will in turn place unnecessary demands on the already confused person with intellectual disabilities and dementia.
- Sheard (2013) emphasises that developing the emotional competency in staff is the only foundation on which progress in dementia care will be sustained and on which dementia care training will finally deliver effectiveness.

Delivery of training

- Dementia awareness training is often delivered to groups of staff from a range of services, often with junior staff attending.
- The only advantage of this model is that it allows staff to meet with colleagues from other settings and to learn from each other. However, this approach rarely results in change in practice once the staff member returns to their care setting. T
- The person who attended the training has to try to 'sell' their knowledge and skills to the staff team, often with little commitment from management to implement changes. Even when this person is designated the 'dementia champion', this rarely results in the needed change in staff knowledge across the whole staff team (Dodd 2014).

- Experience in training staff teams indicates that improving dementia care for people with intellectual disabilities and dementia requires a whole-system approach within staff teams.
- Staff need to understand:
 - what is dementia
 - its specific links to people with intellectual disabilities
 - the signs of symptoms that they need to recognise both at pre-diagnosis and at each stage of the disease.
- However this needs to be underpinned by a model of dementia that helps them to really understand what is happening to the person who they are supporting who is developing dementia, and to be able to put themselves in that person's shoes .

Ongoing support for pro-active management

- Avoiding diagnostic overshadowing (Changes may not all be due to dementia)
- Think ahead and predict the stressors
- Realistic expectations
- Plan ahead for end of life care

Training content

- Training should use a variety of mediums e.g. didactic; group work; use of DVD's; discussions; role plays; case studies; homework tasks. Training can be supplemented by the use of specific resources
- The table below suggests types of training, support and outcomes that should be achieved for each stage of dementia.
- Each stage builds on the information and supports from previous stages and knowledge and ideas can be re-iterated and developed with the staff team.

Stage of dementia	Suggested content of formal training	Suggested on-going support	Outcome required
Prediagnosis:	<ul style="list-style-type: none"> • Signs and symptoms of dementia • The diagnostic process and how to make a referral • Life Story work • Person-centred care plans including health action plan, communication passport, end of life plans 	<ul style="list-style-type: none"> • Understanding the diagnostic process • Working with the person and their family / friends to develop their life story work • Support to develop end of life plans whilst the person has capacity 	<ul style="list-style-type: none"> • Person is supported through the diagnostic process • Other health issues are identified and treated • Social issues are identified and resolved • Plans are in place

Stage of dementia	Suggested content of formal training	Suggested on-going support	Outcome required
Early stage:	<ul style="list-style-type: none"> • Model of dementia (Buijssen) • Philosophy of care • Physical Environments • Importance of picture cues • Medication 	<ul style="list-style-type: none"> • Helping staff to accept the diagnosis and the changes • Grief and loss • Implementing the philosophy of care • Importance of consistency of approach 	<ul style="list-style-type: none"> • Person is supported to maintain their current lifestyle with additional supports and prompts

Stage of dementia	Suggested content of formal training	Suggested on-going support	Outcome required
Mid stage:	<ul style="list-style-type: none"> • Communication • Supporting peers of the person with dementia • Failure-free activities • Maintaining health and additional health issues e.g. epilepsy, mobility, continence • Pain recognition and management • Reminiscence 	<ul style="list-style-type: none"> • Understanding the meaning of behaviours and exploring solutions • Avoidance of confrontation • Understanding and coping with agitation and distress 	<ul style="list-style-type: none"> • Person is supported to live as full a life as possible focussing on preferred activities and reminiscence activities and without unnecessary changes

Stage of dementia	Suggested content of formal training	Suggested on-going support	Outcome required
Late and end stage:	<ul style="list-style-type: none"> • Safe manual handling • Safe eating and drinking • Skin and pressure care • Mobility, falls management, posture and positioning • Meeting spiritual needs 	<ul style="list-style-type: none"> • Support for end of life care for both the staff and their support of the person's peers and family • Support in getting appropriate aids in a timely manner e.g. specialist wheelchair, seating, profiling bed, hoist, bathing aids 	<ul style="list-style-type: none"> • Person receives care that allows them to continue to experience activities and support that is familiar to them • Person is supported in all their daily living needs in a dignified and safe manner • Person experiences end of life care that results in a 'good death' in their preferred place.

Group work

Developing the Top 10 tips

What would you say are the top ten things that make a difference to:

- Families
- Staff

Questions and Discussion?

